



Living with Someone with Chronic Illness

If you're living with and caring for someone with a chronic illness, you've no doubt come across the common perception of the caregiver as heroic and saintly. In reality, there'll be many times when you feel neither of these things. As Chris McGonigle puts it in *Surviving Your Spouse's Chronic Illness*, you are just "an ordinary person in an extraordinary situation" – a situation that can affect your entire family's social life, finances, physical health, and emotional health.

What You May Be Feeling

The thoughts and emotions felt by caregivers can range widely. The initial diagnosis may be greeted with denial or fear of the future. You may be angry at your fate, or even begin to grieve the loss of the person you once knew and loved as his or her illness affects their abilities and appearance.

Coping with these feelings of loss is not easy and you may develop a sense that time is running out. It may be particularly difficult if the person concerned feels he or she doesn't want help or acts in ways that cause problems for him or her and for you.

Once you have accepted the illness, you may try to bear the emotional burden for both parties – feeling guilty that your family member suffers so much. Your relationship may develop in such a way that you feel unable to criticize or express negative feelings toward the chronically ill person. You take on the mentality of the heroic caregiver who must bear all.

On the other hand, there may be times when you feel that the burden is too heavy. You may resent the lack of physical companionship or feel sexual frustration if the person you are caring for is your partner. Sometimes you may just wish that the stress and suffering could end. These secret thoughts may make you feel guilty – and anything *but* the heroic caregiver.

There are no easy solutions for overcoming these stresses and anxieties, but it may help to know that all of these thoughts are normal responses to your difficult situation. Talking about your feelings, whether with a close friend or a trained counselor, really can help – as can the skills and strategies outlined below.

Skills That Can Help

The skills and techniques you'll develop as a caregiver will partly depend on the specific chronic illness, but here are some general tips for caring effectively.

Listen well – Helping the other person talk about their feelings and needs can be a great way to prevent mental health problems such as depression, stress and anxiety. It will also help keep lines of communication open, which is vital to a successful care giving relationship.

Show appreciation and praise – Finding ways to recognize even small achievements without sounding patronizing can boost self-esteem and acknowledge the effort put in.

Touch – Finding ways of touching that feel comfortable or appropriate, like holding someone's hand while talking, can be a simple but effective way to relieve tension.

Laughter – Just because care giving is a serious business doesn't mean you should be serious all the time. Light-hearted use of humor can be a great way to provide relief and distraction.

Doing things together – Wherever possible, try to include the chronically ill person in activities as much as feasible. This will help maintain his or her self-worth and place in the family.

Coping with the Stress of Care Giving

Care giving can be exhausting and emotionally draining. So remember that your needs must be considered as well as those of the ill person. Here are some ways to cope and keep your life as normal and happy as possible.

Accept the illness – Denial of the true nature of the illness can have some short-term benefits if one or both of you need time to process what is happening. But in general, acceptance and honest communication about the illness and its consequences is a better long-term strategy.

Take control of your lives – Both caregiver and the receiver of care need to feel in control of their situation. This can be a delicate balancing act. It's possible to slip into too supportive a role. If you do too much, then the person you are caring for may give up more of his or her independence and decision-making abilities than is necessary. The caregiver becomes a well-meaning enabler and the patient's self-esteem suffers. To avoid feelings of loss of control, encourage a sense of empowerment and independence where possible, and encourage participation in self-help and support groups.

Build a broad network of support – You can't do this alone. Try to involve as many people as you can, whether they be family, willing friends or support groups. The chronically ill person may not be able to get all the practical and emotional help they need from you, and you will need a break from your care-giving role. Research shows that larger households are associated with lower caregiver strain – so if it's just the two of you, try to get more help.

Become an expert in the illness – By researching and knowing as much as you can about the illness, you'll recognize its characteristics, be a more understanding caregiver, and have a better chance of getting the best care you can for the person you are caring for.

Find the right medical team – Try to assemble the best set of medical caregivers that you can – they should be experts in the illness as well as people with whom you can communicate. You may need to be assertive and persistent to get the care needed.

Resolve relationship issues – In order to care effectively and maintain a healthy relationship with the person you are caring for, you may need to sort out any problems so that your relationship does not suffer under the new pressures. This may be especially true with couples. With the losses and stresses caused by illness and its effects, emotional, personal or sexual problems may need to be fixed more quickly than if the couple were both healthy.

Acknowledge your own needs – You need to look after yourself and find some balance. Don't feel selfish if you go out occasionally with other people, or take some time away. Seeing someone you love suffer is painful, stressful and frustrating. You'll need to develop activities and techniques that allow you to relax, recharge your batteries and feel that you have your own life.

Build your own support network – You'll need someone to talk to and ways to share your burden. This may be a friend, family member, or a trained counselor. There are also support networks for caregivers. Caregivers often suffer from fatigue and lack of relief – it is crucial that you get help and take breaks from your role.

**For more information on how MHN can help you cope with a chronic illness,
call (800) 977-7532.**

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